

IRCA ARTICLES

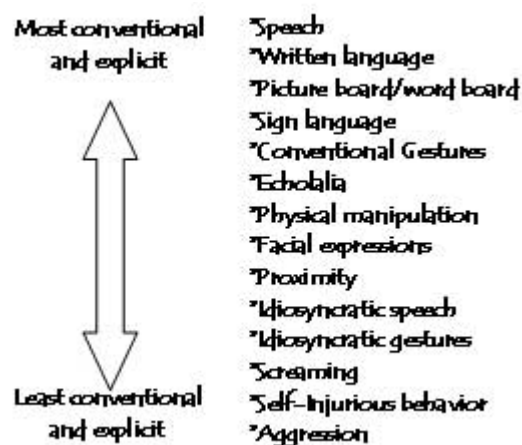
Communication

"If They Could Only Tell Me What They Are Thinking." The Need for Augmentative Communication for Individuals with Autism Spectrum Disorders

Contributed by Kim Davis

Have you ever seen a child and looked into his or her eyes and said, "I know he/she's in there if we could just unlock the door?" Teachers and parents of minimally or non-verbal children with an autism spectrum disorder have felt that way over the years. They have a feeling that the child could tell them things if he or she could only speak. If the child could just tell them what was going on, the right supports could be put into place and life could be better for everyone. Have you ever felt that way?

When we support non-verbal individuals with Autism Spectrum Disorders (ASD), we quickly become aware that it is important to read body language, facial expression, sounds, or other behaviors. We begin to read the messages of those behaviors, which unfortunately is most frequently associated with negative behavior. Behavior IS communication and it is used not only for "negative" means, but also to express joy, happiness, and desires!! How wonderful it would be for those who are non-verbal, to have an alternative means to express their wishes!!



There are various ways to communicate. Most people can speak, which is the most explicit and understood means to express wishes. However, as Barry Prizant shares in this chart – there are many alternatives which can be less explicit and efficient, yet are often used by even those who can speak quite well.

The arrow indicates the flow "up and down" that most verbal people use on a regular and as needed basis. Sometimes the situation may call for a scream or sometimes, we may even "hit" (tap really) ourselves in the head when we forget something. It is wise to consider that if those of us who speak can use various strategies listed on this chart, perhaps those individuals who are non-verbal have the right to do the same. The right to express themselves with the only means they may have available to them—behavior! Sadly, for most of those non-verbal individuals, using their behavior is not seen in a positive manner and yet they are infrequently given or taught any alternative!!

For those of us who speak, there are alternatives used to communicate. E-mail and computer instant messages are

regularly used to communicate with someone, perhaps even someone in the same office or down the hall!! FAX machines display the written word for people in distant locations. Phone calls, voice mail, answering machines, call waiting, and cell phones also allow people a means to get their point across. There are even some individuals who still prefer the good old face to face conversations that includes facial expressions, body language, gestures, proximity, physical manipulation, sounds, or idiosyncratic behaviors!! Each person may communicate better using one method over another or a combination of many; some are better at talking instead of writing or visa versa. We have that option. Non-verbal individuals do not. They only have behavior to express every wish, desire, fear, frustration, or other emotion they might experience. How limiting and frustrating that must feel?

On top of all this, some of us feel more comfortable using one form of communication over another as well as controlling the number of listeners. For some of us, speaking in front of a large group is not an issue; for others, it is completely terrifying. Some of us prefer small groups; while others, would much rather only speak to one person at a time. Each person and situation is different. Even those who are unafraid to speak to a large group, may not feel totally safe to share their deepest secrets or fears with just anyone. TRUST in a relationship allows for a more free and flowing sharing of information. The same is true for individuals who are non-verbal on the autism spectrum. They need to feel respected, valued, and trusted by those who support them both at home and at school before they show themselves and share what they know or feel. If they feel that the person supporting them believes in them and wants the best for them, just like the rest of us when we have people who truly believe in us, things can change and achievements can begin. If there is lack of trust, disbelief in abilities, or mistreatment, any forward progress will be negated.

What should we do to support those non-verbal individuals with an autism spectrum disorder, who have “challenging behaviors,” and frustrate us? First realize they are probably frustrated with us as well!! Next realize their behavior is their communication and they are desperately trying to tell us something. Third, let them know you are trying to understand them and believe that they have true worth and abilities. Last, but surely not least... invest time and energy into seeking an alternative means for those individuals to communicate!! Since each individual with ASD is unique, each may utilize a different manner of communicating. Not every alternative system works for every individual. Therefore, exploring every possible option is necessary. If we truly want to help them communicate and alleviate their need for using behaviors to get their point across, we need to be bold and leave no communication system or style untouched. What works for one, may not work for another.

There are websites that list various alternative and augmentative means to communicate. There are companies that produce and sell communication devices. There are many books on types of communication. There are methods that are controversial, but that do work for some. There are individuals and organizations who train others about augmentative communication. There are individuals who use alternative means to communicate who are speaking of their right and the rights of others to have a voice. They are demanding that all methods of alternative communication be investigated and tried with non-verbal individuals. It is sad when those of us who can speak, and are supposed to be seeking the best support possible for these individuals, eliminate potential methods of communications that might work. What does it hurt if a method is tried in a thoughtful, respectful and thorough manner? If it works, how wonderful might that be for everyone? If it does not, back to the drawing board to seek another way.

Challenging behaviors are there for a reason, as are all behaviors. Those of us who support individuals with ASD who are non-verbal owe it to them to leave no rock unturned when it comes to seeking alternative communication. The longer they have no other means to communicate, the longer teachers and parents will have to decipher challenging or excited behaviors. The world could become more open, accepting, and exciting for everyone if these people had their voice—however it is meant to be heard!!

Resource List

Internet sites

American Sign Language Browser: <http://commtechlab.msu.edu/sites/aslweb/browser.htm>.

This is an online American Sign Language (ASL) browser where you can look up video of thousands of ASL signs and learn interesting things about them.

Augmentative Communication Inc: http://www.augcominc.com/index.cfm/aci_links.htm.

Provides information and services relevant to the Augmentative Alternative Communication community such as AAC Organizations, AAC Device Vendors, and AAC-related Product Vendors.

Augmentative Communication Consultants Inc: <http://www.acciinc.com/>.

Augmentative Communication Consultants, Inc. (ACCI) represents over a dozen manufacturers of augmentative communication and other assistive technologies, offering demonstrations, workshops, and consultation.

International Society for Augmentative and Alternative Communication: <http://www.isaac-online.org/en/home.shtml>.

ISAAC (International Society for Augmentative and Alternative Communication) is an organization devoted to advancing the field of Augmentative and Alternative communication (AAC). The Mission of ISAAC is to promote the best possible communication for people with complex communication needs.

Facilitated Communication Institute: <http://soeweb.syr.edu/thefci/>.

Facilitated communication is an alternative means of expression for people who cannot speak, or whose speech is highly limited (e.g., echoed, limited to one or a few word utterances), and who cannot point reliably.

Picture Exchange Communication System (PECS): <http://www.pecs.com/page5.html>.

PECS begins with teaching a student to exchange a picture of a desired item with a teacher, who immediately honors the request.

PATINS: <http://www.patinsproject.com/>

The PATINS Project is an Indiana Department of Education assistive technology systems change initiative. The project is made up of five regional sites. The project is designed to impact both the organizational capacities of local public schools and the professional capabilities of school staff in the delivery of assistive technology services and the implementation of Universal Design for Learning Principles.

PATINS has established lending libraries at each of our five operational sites. Equipment, software, videos, and print materials are available to public school staff for preview and evaluation purposes. In addition, PATINS offers workshops, both onsite and offsite, and offers technical assistance to local school personnel on specific devices.

PATINS also provides recycled computer technology to qualifying public schools for use with disabled, disadvantaged, and/or at-risk students.

Articles from IRCA

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Davis, K. (2005). "If they could only tell me what they are thinking." The need for augmentative communication for individuals with autism spectrum disorders. The Reporter, 10(1), 4-6, 16.